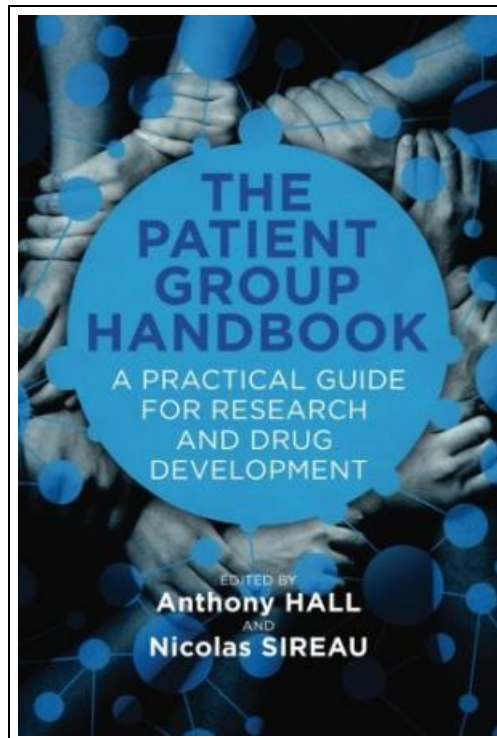


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THE PATIENT GROUP HANDBOOK: A PRACTICAL GUIDE FOR RESEARCH AND DRUG DEVELOPMENT (PAPERBACK)



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Createspace Independent Publishing Platform, United States, 2016. Paperback. Condition: New. Language: English . Brand New Book ***** Print on Demand *****. This new book edited by rare disease experts Anthony Hall and Nicolas Sireau provides a collection of chapters by world leaders in the field of orphan diseases and drugs in order to help patient groups grow fast and sustainably. As a practical, hands-on guide for research and drug development, it provides tools and advice on topics such as: - How to set up and manage a patient group: US and UK perspectives. - How to build an international research consortium. - How to promote basic research. - How to engage with academia for drug discovery. - How to engage with industry. - How to set up a centre of excellence. - New funding strategies for clinical research. - Crowdfunding for rare diseases. - Practical thinking to win bids. - Orphan drug legislation and adaptive licensing. - Early interaction with regulators and parallel scientific advice with health technology assessors. - How to navigate the regulatory process. - Empowering children to become involved in the research agenda. - Natural history studies. - Clinical efficacy measures and surrogate endpoints. - Statistical considerations. - Setting up and running a clinical trial. - Patient registries. - How to interact with government and lobby for change to the clinical trials system. - Patent protection and ownership of patents. - Engaging patients and carers online for clinical trials. If you are involved in patient groups or rare diseases in any way, then this book will provide valuable reading. All royalties from sales of this book are being donated to the charity Findacure, which provides support to rare disease patient groups.



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